3

Community involvement in evaluation research

Towards transformation

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LEARNING OBJECTIVES

After reading and reflecting on the content of this chapter you will be able to:

- Recognise the importance of defining 'community'
- Use tools to describe levels of community involvement
- Describe common principles of community involvement as well as challenges
- Outline principles of co-production as a desirable model for community involvement
- Suggest approaches to involve communities at all stages of the evaluation research cycle

Reflexivity statement

The authors of this chapter are a collective with experience in community-based and community-led work across a range of health issues. We are committed to promoting meaningful community involvement at every stage of intervention research, driven by our commitment to improving health outcomes and advancing health and social justice. Some authors draw on their lived experiences of marginalisation and silencing as members of historically minoritised communities as part of this process (RAB, ND). Others bring long-standing experience working with marginalised communities, acknowledging their privileged position as researchers without direct experience of marginalisation, but with a strong commitment to learning and redistributing power (LP, AP, AD). All authors work continually to advance meaningful community involvement in public health landscapes globally.

3.1 INTRODUCTION

The goal of public health evaluation research is to generate reliable evidence about the appropriateness, **feasibility**, **acceptability**, **efficacy** and **effectiveness** of approaches to improve health outcomes. Ideally, this should be approached in ways that avoid entrenching existing health and social inequities. Community involvement is now widely recognised as a crucial element to achieving this goal, as it contributes to both the appropriateness, quality and fairness of research. Without community input, researchers risk focusing on issues that may not align with the priorities of the communities they aim to serve, recommending ill-fitting interventions or misinterpreting the **impact** of interventions. Such actions waste resources and goodwill, ultimately entrenching health and social inequities. In contrast, meaningful community involvement helps ensure that researchers focus on issues that matter to communities, develop interventions that work and interpret their results in accurate ways. Community involvement requires a commitment to fostering participation from diverse social groups and an ability to navigate often conflicting political and social interests. Doing so effectively requires mobilising expertise from a range of domains, including science, and art and political action, which makes it one of the most exciting areas of public health evaluation research. It also makes it a complex landscape to traverse, requiring solid understandings of the why and how of community involvement.

This chapter is divided into two sections. In the first section (3.2), we explore definitions of community, approaches to community involvement, common principles and challenges, and co-production as a reccomended model for involvement. In the second section (3.3), we discuss opportunities for community involvement throughout the research lifecycle. We conclude with a summary (Section 3.4) and reflective self-learning exercise (Section 3.5).

3.2 FRAMING COMMUNITY INVOLVEMENT

3.2.1 Who is 'the community'?

The term 'community' is highly contested, but in health contexts it is often understood in terms of four common 'types': (1) communities of place, which include shared geography or spaces; (2) communities of identity, which include those linked to shared characteristics, such as a diagnosis, gender or ethnicity; (3) communities of practice, which include people organising around a shared interest or ideal; and (4) communities of shared experience, such as diverse actors brought together by common experiences or events (MacQueen et al., 2001). Some of these communities are 'passive', meaning they are linked to characteristics that individuals may or may not choose to identify with, while others are more 'active', defined by choices, shared activities and intentional engagement.

Defining community is a powerful act that can have both positive and negative consequences. For example, the term 'key populations' – often used to refer to groups such as sex workers or men who have sex with men – has been valuable in advocating for resources and drawing attention to underserved populations in HIV response efforts. However, the label key populations has also been critiqued for reinforcing stigma and discrimination, and for failing to acknowledge the diverse identities within these groups (Barr et al., 2021; Olakunde and Adeyinka, 2024). Defining marginalised populations without addressing the underlying systems that create marginalisation and inequities is often counterproductive, and can lead to additional misrepresentation and harm for those who inhabit these groups.

Evaluation work must therefore recognise that the boundaries of community are largely shaped by power dynamics – who is doing the defining and who has the power to challenge externally imposed definitions (Burgess, 2023). Box 3.1 presents a case study highlighting the challenges of defining and engaging with the community in the **context** of sex work in the UK.

We must also acknowledge the dynamic nature of community and its ability to evolve through collective learning over time (Wenger, 1996). Community is never static and should be acknowledged as something that is living and constantly being negotiated by those within, and those working with, communities. Some approaches to community involvement embrace a more flexible definition of community, even noting that work within the health landscape often results in the creation of new communities that bridge the worlds of research, practice and lived experience. For example, Filipe, Renedo and Marston's work in community involvement in relation to sickle cell (2017: 6) highlights the development of 'new communities, interactions, practices, and different modes of knowledge and value production' as a key benefit of co-production (see Section 3.2.3 for full definition of co-production).

In this chapter, we embrace a more fluid definition of community, defining it as a collection of various actors or groups of people potentially affected by an evaluation, including those who are using, providing, advocating for or otherwise involved in the intervention being evaluated. We view communities as sites of praxis, or shared action, where multiple communities – such as those from research, service provision and lived experience – interact and change. These interactions may even involve communities working with or through conflict. Such conflicts can be acknowledged and harnessed constructively, as illustrated in the case study in Box 3.1.

In the next section, we explore approaches to community involvement.

3.2.2 Lineages of community involvement

Community involvement in public health evaluation research encompasses a variety of approaches aimed at including community voices in one or more phases of a research project, such as its design, **implementation** or interpretation. In this chapter, we treat participatory research and community involvement as closely related, though both can involve a wide range of activities and levels of engagement.

In the participatory research tradition, community involvement entails sharing power with the communities being studied. Participatory research has roots in Latin American and West African decolonial movements, which demanded a citizen-oriented approach to developing and sharing knowledge (Leal, 2007). As a result, participatory research in its modern forms is anchored to principles, values and practices aimed at fostering community involvement. This includes collaboratively selecting the research topic, designing and conducting the study, and jointly analysing and acting on results (Israel et al., 2013). Key traditions include Community-based participatory research (Horowitz, et al., 2009), participatory action research (Lewin, 1946; Cornish et al., 2023) and transdisciplinary action research (Strumińska-Kutra and Scholl, 2022).

Additionally a body of tools from the field of citizen participation[1] can help us understand the depth of involvement in evaluation research and how we might position our own. For example, theories of participation typically use typologies or continuums. Typologies include Arnstein's classic 'ladder of participation' (1969), in which the ladder's lower rungs describe situations where people have very little power and their inclusion does not lead to meaningful change or involvement. Conversely, the top rungs of the ladder of participation describe situations where interventions are largely led by communities (for example, partnership, delegated power or full citizen control).

[1] Note that citizen participation, defined as 'a process which provides private individuals an opportunity to influence public decisions' (Creighton, 2005), can overlap with but is usually broader than citizen science – for example, involving members of the public in scientific research, typically in data collection, analysis and sometimes co-design of research questions (Bonney et al., 2009).

BOX 3.1 CHALLENGES IN DEFINING AND WORKING WITH THE 'COMMUNITY'

The East London Project, UK

The East London Project was a participatory initiative aimed at evaluating the impact of removing police enforcement sanctions – such as arrests, displacement from street-based sex work areas, fines and other penalties – on sex workers' experiences of violence and mental health in the UK (Elmes et al., 2022). The evaluation used a mixed-methods design developed collaboratively with sex worker organisations, sex workers and activists, through initial discussions and subsequently participation on a project advisory board or as co-researchers conducting interviews. Through these mechanisms, key 'communities' contributed to shaping the research questions, study design, data collection and interpretation.

One of the early tasks in the project was defining the sex worker community to be included in the evaluation. We discovered that cisgender men, trans men and trans women were often excluded from discussions on sex workers' health, with media attention and **policy** debates typically focused on cisgender women. To address this omission it was agreed to include a diverse range of participants in the research, representing different genders and work locations, to better inform the policy debate.

Exposure to policing and working practices varied by both gender and work location. Cisgender men generally worked in clubs, where there was low visibility and minimal police contact, while cisgender women working on the street faced constant policing, primarily due to drug use, displacement from public areas or fines for soliciting sex work. In contrast, cisgender women working in off-street settings had less police contact, and when they did, this was mostly related to immigration issues.

These variations had practical implications for the research. First, we were essentially recruiting from three distinct populations and required extensive mapping to create a representative sampling frame. We also had to define and measure different types of exposure to policing and its **counterfactual** removal (Walker et al., 2024).

Our co-researchers and advisory group assisted with the mapping and facilitated **recruitment** of these populations. However, in retrospect, more careful exploration of the practical implications of operationalising a diverse definition of sex work in the research would have streamlined the process. Building consensus across the team early on about this definition would have helped develop a methodology that was both acceptable to the community and conducive to producing new evidence to inform policy and practice.

Continuum-based approaches to participation create opportunities to understand how different actors are enabled or hindered in their research involvement. For example, social psychologists Campbell and Jovchelovitch (2000) have argued that participation should be viewed as a process shaped by symbolic and relational dynamics. Different actors can either support involvement by providing resources and devolving power, or hinder it by establishing rigid boundaries that dictate how and why actors relate to each other in intervention evaluation research. Using typologies or continuums to characterise potential or actual community involvement in public health evaluation research can help locate one's research within the range of approaches to community involvement.

Clarifying the type and level of participation in research is also vital because terms like 'patient and public involvement', 'co-production' or 'co-design' often have multiple meanings (Masterson et al., 2022; Madden and Speed, 2017). Each of these terms has been used by health researchers to describe a spectrum of activities, from brief, top-down consultations to long-term collaborations that create equitable communities of practice between researchers, patients, members of the public, health providers and policymakers.

The UK's National Institute of Health and Care Research (NIHR) makes a helpful distinction between community *involvement* and public *engagement*, which reflects an attempt to differentiate between different levels of participation: 'involvement is research done *with* or *by* patients and the public, not to, about or for them'. It is about working collaboratively with patients and the public and sharing decision-making. On the other hand, engagement focuses on 'raising awareness, sharing research knowledge and findings' (NIHR, 2021). In this chapter we also view engagement as the most limited form of community involvement. We constrast it with co-production as a more deliberate and explicit attempt at power-sharing or 'partnership' with communities, and moving towards a goal of transformation of communities and researchers within a collaborative process of research. In the next section, we explore co-production as the most desirable model of community involvement because it involves a commitment towards more in-depth and equitable partnerships, with a wide range of benefits for communities.

3.2.3 Towards transformation: Co-production as the goal?

Co-production has various definitions (Masterson et al., 2022) but in health contexts, it is generally understood as a process aimed at fostering shared responsibility for health governance, **monitoring** and care among diverse actors, including active citizens and patients (Kickbusch and Glischer, 2012). Burgess and Choudary (2021) advocate for a more politically oriented perspective, envisioning co-production as a multi-phase process that enables intervention beneficiaries to meaningfully participate in designing and evaluating interventions. Drawing on theories on transformative participation (White, 1996), Burgess and Choudary's model (2021) of co-production

draws attention to key processes, such as dialogue and the identification of shared goals, and gradual implementation of community-building activities to create a safe space for collaboration among groups from different social and societal positions. Such an approach to co-production acknowledges a key fact in all community involvement work: before involving numerous actors in shared practices, such as question development, design or evaluation, efforts are required to acknowledge historical relationships between actors, recognise past hurts, and establish new hierarchies of knowledge that take the contributions of community members and lived experience seriously (Burgess, 2023).

Co-production has also been described as a site of quiet activism (McMellon et al., 2023), highlighting its potential to focus on transformation of not just outcomes, but also people, aligning it with principles necessary to decolonise knowledge and practice (Smith, 1999). This means doing research that is transformational in nature and that leads not just to alternative ways of producing knowledge (research methods/methodology) but equally to tangible outcomes that work to benefit disadvantaged groups.

Burgess (2022) presents a staged approach to conceptualising community involvement (see Table 3.1). This framework outlines the progressive evolution of community engagement, recognising that every study – and every stage of a researcher's career – comes with different levels of access to power and capacity for transformation.

Table 3.1 Attempting transformation in global health (adapted from Burgess, 2022)

The dream: Co-owned research with communities through co-production	Where possible: Co-design sharing responsibility of decision-making	At minimum: Inclusive methods and acknowledgement of contributions
• Co-produced questions, strategy (priorities and goals are identified with the community) and research process (including funding, implementation and interpretation) • Long-term relationship and resources that allow communities to experience change • Transfer of power and resources is the **outcome** (in other words, building foundations for future independent work needed) • Impacts occur during the research process (social impacts, power shifting, and so on)	• Open and flexible research questions • Co-design and shared practices of research/project implementation • Action to ensure **transferability** and impact after the study	• Participatory methods used where research questions are pre-determined by one group • Compensation and partnership system to reflect understandings of local need • Reflection and action on transferability of outcomes and impact after the study
Likely actors: Senior/protected academics and evaluators at top of current power structures with flexibility to push boundaries	Likely actors: Mid-career academics and evaluators locked within difficult systems, but some control over design	Likely actors: Early career or precarious researchers or staff with limited control over design

The ultimate goal is to create research processes that facilitate power-sharing, encourage collaborative development of research questions and methods, and involve community members at all stages. However, it is equally important to avoid forcing such engagements, as meaningful community involvement requires adequate resources – including the emotional investment of researchers (both within and external to communities) themselves – to drive genuine transformation. For example, a statistically oriented research question may not be well suited to the immediate equal involvement of community members, in the absence of strong investment in developing their skills so they may meaningfully participate as researchers. Furthermore, topics explored in research could also result in retraumatisation for community researchers who have lived experience of an issue. As such, community researchers will need freedom to accept or reject involvement with particular aspects of the research, and access to resources for practical or emotional support during the research process.

In the case study of co-production to develop and evaluate a mental health intervention in Colombia, described below in Box 3.2, all three stages of community involvement were applied in one study, to ensure the transformative opportunities of the research project. First, the use of inclusive methods meant that all community members who acted as participants were able to more meaningfully shape research outcomes and design. Second, hiring of a small group of community members to be community researchers meant they were able to be trained in **qualitative** and **quantitative** research methods, allowing them to be involved in co-design strategies. This also allowed them to contribute to strategy and ownership of the directions of the project. Finally, the study was established based on long-standing partnerships with non-governmental organisations (NGOs) and community leaders, who established priorities, set research questions, authored sections of funding applications and established new opportunities for future independent work during the project.

The key principle underlying co-production is the pursuit of equity of power, meaning that everyone involved in an evaluation is of equal importance. This requires a recognition that power is often rooted in wider social and economic differences and needs to continually be addressed in ongoing relationships. Co-production frameworks should be used to challenge hierarchies of knowledge production and related epistemic exploitation.

3.2.4 What is 'meaningful involvement'?

At the heart of co-production and other approaches to community involvement is a struggle with defining 'meaningful involvement' within any specific research projects. Approaches to community involvement all share a common commitment to fostering meaningful, two-way dialogue to enhance the quality and relevance of research. These approaches uphold the principle that communities have a fundamental right to participate in planning and delivering public services, recognising their knowledge as

BOX 3.2 CO-PRODUCING A MENTAL HEALTH INTERVENTION IN COLOMBIA

In Colombia, the prioritisation of mental health has emerged as part of a national peace and reconciliation process following over 60 years of internal conflict. However, mental health-oriented work typically does not involve community members in the process of intervention development, instead applying standardised approaches (such as the World Health Organization's (WHO's) Mental Health Gap Action Programme or initiatives led by smaller NGOs in local communities). The STARS-C project was a collaboration between academics at University College London, the London School of Economics and Political Science, Universidad de Los Andes, and two community-led organisations working in rural communities: COOMBUVIPAC and Corpo Manigua. A co-production process allowed us to meaningfully engage with community actors at three levels: overall research design, where NGO collaborators were part of the primary investigator team, contributing to funding applications and framing original research questions and design; intervention design implementation; and evaluation processes.

At the overall research management level, our co-production approach supported the establishment of a horizontal management structure for the whole project, with representatives from each organisation as co-investigators. This initial team worked to develop the broad orientation of the research. The team decided on the use of participatory action research (PAR) cycles to structure work with groups of everyday community members to co-develop, co-design, pilot and co-evaluate a community-action intervention to improve mental health (Burgess, 2022).

At the research design and implementation level, we appointed five local community researchers, who lived in local communities, worked for the duration of the project and were trained by the academic team on participatory research skills, ethics (including mental health first aid) and PAR methods.

The PAR cycle was run with community members and actively engaged everyday citizens in the research process throughout. In the 'diagnostic' stage, community researchers facilitated group dialogues and focus group sessions to identify shared priorities (definitions of 'mental health', local community needs and struggles) to structure the intervention. They also discussed and explored different evaluation tools, discussing their relevance, and their ability to capture their experiences and be understood by members of the community. The diagnostic stage ended with a **theory of change** workshop, where community members helped to design the structure of the STARS-C intervention, organised around community-defined issues, their specific mental health concerns and hopes for the future that the intervention could contribute to.

The final intervention content was developed by the community researchers and project management team. It comprised of a 12-week long intervention, organised around participatory learning and action principles. In stage one, community members studied mental health topics, learned about their rights, identified key issues they would like to solve in their communities and pinpointed strategic partners in wider social institutions that could provide support in achieving their goals. Stage two was organised around implementing their local action projects. In stage three, group members evaluated their projects, using **photovoice**. One hundred and twenty community members contributed to the design and piloting of the novel intervention, ending with a participatory photovoice evaluation of the impact of their community action projects. The community action projects they designed included a range of activities that responded to both the experiences and sources of distress: educational interventions (increasing access to mental health information; increasing access to higher education for young people), physical health interventions and income-generating projects. The approach overall was identified as 'transformative' by community members. It gave them the chance to change the social and structural drivers of poor mental health, and develop feelings of confidence and agency – and it had an impact on mental health outcomes (our formal evaluation identified significant reductions in poor mental health, based on Patient Health Questionnaire-9 scores).

essential to understanding how systems, services or interventions function. This principle was enshrined in the WHO's 1978 Alma-Ata Declaration (Rifkin, 2018).

Meaningful involvement is grounded in the right of people to actively and meaningfully engage in decisions that affect their lives. Statements like the *Global Consensus Statement on Meaningful Adolescent and Youth Engagement* (Partnership for Maternal, Newborn and Child Health, Family Planning 2020 and International Youth Alliance for Family Planning, 2020) and the *WHO Framework for Meaningful Engagement of People Living with Noncommunicable Diseases, and Mental Health and Neurological Conditions* (WHO, 2023) outline key principles:

- Rights-based: Ensures involvement is rooted in fundamental human rights
- Transparent and informative: Provides clear and accessible information
- Voluntary: Free from coercion
- Respectful: Values diverse views, backgrounds and identities
- Safe and people-centred: Prioritises participant safety and wellbeing
- Equitable: Addresses power imbalances and fosters fairness

There is always opportunity for improvement. For example, an analysis of four case studies involving young people as partners in health research across three African

countries found both successes and challenges (Doyle et al., 2022). While many youth engagement activities aligned with the *Global Consensus Statement on Meaningful Youth Engagement*, participation was often uneven. Marginalised young people still faced barriers to involvement, and key design decisions had often been made before their involvement. As evaluators, we must continuously strive for meaningful involvement by reflecting on our progress and how to address the common challenges to involvement outlined below.

3.2.5 Challenges in community involvement

Practical constraints often limit the ability to achieve meaningful community involvement, particularly in short-term research evaluations. Ethical issues include risks, such as placing a high burden of expectation on communities, wasting participants' time, over-promising outcomes or raising unrealistic expectations for immediate action. These risks can be mitigated through transparency about the project's scope and the potential benefits for participants, as well as by adequately resourcing involvement. Furthermore, true partnership would mean that communities have the ability to dictate the nature of involvement – meaning they may chose to take a back seat in certain areas and be a driving force in others. Supporting participants in meaningful engagement, such as by providing training, interpreting technical protocols, and offering sufficient time, space and compensation to enable participation, is crucial.

Berenstain (2016) highlights that marginalised populations are frequently excluded from health-related discussions or relied upon to educate academics and privileged communities without adequate compensation or recognition as experts in their own lives. Power imbalances in voice, position and representation present significant challenges to equality in co-production and all forms of community involvement. Diversity in participation is essential to ensure broader community representation. Self-selecting participants may not reflect the wider community, and while their expertise is valuable, strategies are needed to include diverse voices. These strategies include:

- Conducting engagement activities in convenient community locations, such as community centres or other local spaces, and at convenient times for the participants, for example outside of working hours
- Offering digital participation options while remaining mindful of access barriers, for example relating to data or internet connections, for some individuals
- Avoiding reliance on participants visiting researchers in university or hospital settings during standard office hours, which may be inaccessible due to geography, disabilities, childcare responsibilities or other constraints

Box 3.3 illustrates challenges to community involvement to develop and evaluate an intervention with people who use drugs in the UK.

BOX 3.3 NAVIGATING OPPORTUNITIES AND TENSIONS IN COMMUNITY INVOLVEMENT

Safe inhalation pipe provision (SIPP)

The SIPP project was an academic-community partnership to evaluate an intervention (the provision of safe inhalation equipment and advice) to reduce the harms associated with crack cocaine use (Harris et al., 2024). The project developed following weekly online meetings held to monitor and facilitate swift response to drug-related harms during the COVID-19 pandemic in the UK. The online platform facilitated attendance from a core group of people who used drugs, drug treatment providers, public health policy leads, researchers and police constables across the UK. The vulnerability of crack smokers to respiratory harm and COVID-19 transmission was an early concern (Harris, 2020).

There were no inhalation equipment or pharmacotherapy interventions at drug treatment services, so unless one required needle/syringes for injecting or was on opioid substitution therapy, there was little incentive to attend a service for people using crack. Peer networks in some areas were instrumental in providing safe injecting equipment during the height of the COVID-19 pandemic, when pharmacy and drug treatment service provision was limited. The project team collaborated with these networks on a grant application to develop and evaluate an intervention distributing safe inhalation equipment and training, with approvals from local police forces at intervention sites. Evaluation focused on understanding the effect of the intervention on reducing health harms (sharing of pipes or using homemade pipes) and increasing engagement at drug treatment services. Peer networks advised on recruitment strategies and were crucial to accessing people not using services.

Key learnings from community involvement included the need to be adaptable when things did not go as planned during intervention delivery and data collection for the evaluation. Managing dominant voices claiming to represent the wider community was initially a problem and required careful negotiation to ensure that expertise was acknowledged but not at the expense of sidelining others. Setting up fieldwork times or intervention delivery was often time-consuming when people regularly switched phones and were difficult to contact. While drug treatment services provided support and referrals for peer researchers, there were also challenges in managing relationships across the team. Clear geographical boundaries were needed to avoid overlap in work of peers and drug treatment services to avoid their different approaches causing tension. Collaboration with peer networks not only facilitated access to people not using services, but their presence also provided reassurance to participants when interviews were conducted in community settings.

Having peers and researchers running workshops and focus groups with people who use crack was invaluable. They were enthusiastic about seeing peoples' pipes, respectful of the self-protective strategies they undertook and enacted in their daily lives, and affirmed their expertise. This approach was critical in establishing trust between the community and research team.

In the next section, we describe opportunities for community involvement at each stage of the research lifecycle, using the UK Medical Research Council (MRC) framework for the development and evaluation of complex interventions to structure our discussion.

3.3 COMMUNITY INVOLVEMENT ACROSS THE EVALUATION CYCLE

Public health interventions are often complex because they involve multiple interacting components (Craig et al., 2008). For example, a school-based intervention to improve children's diets might include training for school staff, actions to limit the availability of unhealthy foods in schools and curriculum-based interventions to promote healthy diets. The MRC framework for the development and evaluation of complex interventions describes four key stages in the research lifecycle (Skivington et al., 2021) (also see Chapter 2). First, an intervention is developed based on evidence and **theory** about the health problem being considered, or an existing intervention is selected based on existing evidence and local appropriateness. Second, the chosen intervention and potential evaluation design are assessed for feasibility and acceptability. Third, an evaluation is conducted using appropriate methods to address the main research questions (for example, questions about effects on clinical outcomes or about whether intervention processes functioned as planned). Finally, further research is conducted at scale, in the context of routine implementation, to increase the impact and uptake of the tested intervention. Importantly, this framework does not dictate *who* should be doing the development and evaluation. For each of these, researchers need to decide on the extent to which they wish to share power with the various communities potentially affected by the research, through community involvement. Specifically, community involvement can be used at each of the four stages of the MRC framework to:

1. Identify and understand the health problems that matter most to those concerned, and define options for intervention;
2. Understand who can assess which interventions are feasible and acceptable, and how to interpret data on feasibility and acceptability;

3. Ensure that evaluation approaches are fit for complex interventions and do not reinforce pre-existing health and social inequities;
4. Ensure that communities' own interpretations of findings are given due importance as well as help define options for further implementation and scale up.

We expand on each of these below.

3.3.1 Developing or identifying interventions

As O'Cathain, et al. (2019: 5) state: 'The rationale for involving relevant stakeholders from the start . . . is that they can help to identify priorities, understand the problem and help find solutions that may make a difference to future implementation in the real world'. Community involvement during intervention development is so important because the selection of a problem, the conceptualisation of what drives it and decisions on how best to address it shape all subsequent phases of work.

As discussed in the previous section, community involvement may take many forms. In some cases, there may be an existing system linking researchers, community members and other stakeholders. In other cases, the development of an intervention brings researchers, community members and service providers together for the first time. It is important that sufficient time is given to building relationships at the start and creating a shared understanding of who the community includes and how community involvement in the development and evaluation of a new intervention will work. Where an existing set of partnerships exists, researchers (who may be new to the setting) need to take time to understand the setting and how the current piece of work builds on previous collaborations (Mellor et al., 2023).

Another important consideration is the resources needed for effective community involvement. During the initial stages of an intervention's development, financial and practical resources are sometimes available from universities, research and programme funders, or communities themselves to support intervention development. This is an important point at which to consider skills development and training needs for all those involved in the partnership. Members of communities affected by the research might bring differing levels of understanding of the research process, while researchers may need to develop their skills in working with non-academics, managing power dynamics and ensuring that different voices are heard. Similarly, community members might need support to listen to marginalised groups from their own communities. Some participatory research activities have strategies to facilitate this. For example, 'the power walk activity' is a group role-playing exercise designed to facilitate reflection on power, privilege and social inequalities, which is widely used in health and with a range of actors. Participants are asked to 'walk' in someone else's shoes and experience what it feels like to be powerless or powerful based on

gender, occupation, education level, disability, age or status when faced with different opportunities or obstacles (Office of the United Nations High Commissioner for Human Rights, 2014).

As discussed in Chapter 2, defining the problem to be addressed by an intervention is an important first step. There is a long history of researchers and policymakers (with limited or no connection to local communities) identifying interventions that either do not address the needs of communities or that are not acceptable to them. Community involvement at this stage of the process, therefore, enables key priorities to be identified and informed by an understanding of context. This can relate to assessing the rates or **prevalence** of a health issue, but also their salience to different social groups. There are decisions to make about how a particular problem should be conceptualised. For example, research on the needs of young men in inner-city Chicago (USA) found that many felt community violence prevention and safe parks were critical to wellbeing (Rigg et al., 2019), so that any initiatives to 'green the city' would need to consider young men's safety if they were to succeed – an insight which might otherwise have escaped policymakers.

Defining problems in partnerships with communities raises important issues of power, both in relation to listening to diverse voices, and how different kinds of knowledge are valued and integrated. Activities which build partnerships may inadvertently reinforce existing power relationships or the exclusion of certain voices. For example, certain forms of collaboration building (for example, through formal meetings) may exclude those who feel uncomfortable within these spaces. It is therefore important to consider how to facilitate access to the research process for diverse groups, and ways to centre the voices of marginalised groups.

Once the problem to be targeted is agreed, community involvement is key to developing the outline of a new intervention. This includes understanding which aspects of the problem may be modifiable (and which may not) and how to design interventions to address these aspects. Communities – all those potentially affected by an intervention – can help ensure it is suited to the context into which it is being introduced. This involves both the 'cultural' fit of the intervention and best systems for implementation.

3.3.2 Pilot testing for feasibility and acceptability

Feasibility/pilot studies are future-oriented and typically address two sets of questions. First, they take the initial version of an intervention and assess the feasibility of implementing it across different contexts and its acceptability to communities potentially affected by it, including implementers. Community involvement can generate valuable insights into the acceptability of the intervention (and the extent to which it meets community needs), development of strategies for recruitment and retention, and suggestions on systems and structures for sustainable implementation.

The feasibility stage offers important opportunities to refine the intervention's **logic model** (in other words, our understanding of how it brings about intended outcomes). Feasibility studies will often involve delivering the intervention across multiple sites, and it is important to understand how the needs of communities and the 'fit' of the intervention may vary across contexts and types of communities (for example, healthcare workers v. managers).

Second, feasibility studies consider the extent to which it will be feasible to undertake a large evaluation that assesses the effectiveness of the intervention. This encompasses understanding the feasibility of using specific study designs, data collection methods and outcomes. Community members will bring critical insights on the feasibility of proposed research designs. These inputs can allow researchers to determine whether to continue with their planned research design, to modify it or to co-produce a new design entirely with communities. Low recruitment and retention are key challenges to the successful delivery of all intervention studies; again, community members are likely to provide critical input on potential strategies to overcome these challenges. Co-production approaches promote community ownership of research, which can in turn help support recruitment and retention.

During the feasibility phase, researchers will want to look at the acceptability of data collection tools, such as questionnaires or interviews, including their content, length and whether improvements can be made. Members of the community will have valuable insights into which issues could be explored in more depth. For instance, Ricciardo et al. (2024) undertook a 'Healthy Skin pilot' designed to address skin infections and associated health disparities among Aboriginal children in urban Australia. The research team worked with local Noongar Elders, a research forum within the Telethon Kids Institute, as well as health clinic staff. Following feedback from these groups, changes were made to the study's **protocol**, such as attending to the 'cultural appropriateness' of study materials, widening the eligibility criteria for participation and identifying issues needing additional exploration.

An important function of feasibility studies is often to determine whether or not a larger evaluation – designed to evaluate an intervention's effectiveness – should go ahead (see Chapter 2 for more detail). Recent published guidance on progression criteria highlights the value of involving a range of stakeholders (including public or patient representatives) in the development and assessment of these criteria (Mellor et al., 2023).

3.3.3 Examining the efficacy of interventions

Community involvement should inform ethical, design and analytic decisions within efficacy evaluations of public health interventions. Involving community members through advisory boards and/or qualitative research can help guide the ethical conduct

of evaluations. For example, communities can guide assessments about **equipoise** (that is, genuine uncertainty about the balance of benefits and harms for a set of interventions). This is vital to ensure communities participating in evaluations with counterfactuals (for example, **cluster** randomised controlled trials (**RCT**s)) agree that a trial with a **control group** is warranted and acceptable. This is particularly important where large power differentials exist between researchers and study participants, and where the interventions being tested are highly likely to have *some* benefit given pre-existing socioeconomic disadvantage and lack of services, irrespective of its effects on a trial's **primary outcome**. This might for example be the case in trials of unconditional cash transfers to improve a range of social, economic and health outcomes, or trials of infrastructure known to benefit public health in most settings, for example toilets (Howard, 2022; Clasen et al., 2014). Lack of community involvement in assessing equipoise for such evaluations can result in what has been described by London (2001: 312) as 'exploitation of the brute fact of social deprivation' for researchers' gain, and contributes to reinforcing social and **health inequities**.

Additionally, communities can help define appropriate standards of care in trials, ensuring interventions align with local needs. For example, a trial testing a suite of participatory community interventions to improve the school attendance, mental health and nutrition of adolescents in eastern India (the Jharkhand Initiative for Adolescent Health or JIAH) also included livelihood promotion activities for families in both intervention and control arms, following recommendations from community members (Bhatia et al., 2022).

Finally, communities can help to identify appropriate cluster guardians (local representatives) who can legitimately give consent on behalf of their area or services, or identify other strategies to appropriately seek community-level consent for research participation (Osrin et al., 2009). This is important given individuals in a geographic cluster often do not have a say about whether their cluster will participate in an evaluation or not, and are effectively only asked for their individual consent in relation to data collection. As discussed above, understanding who can speak for any given community is often challenging, so consulting widely about appropriate cluster guardians can help support ethical consent processes. The two final concerns discussed here (standard of care and cluster consent) extend beyond RCTs and are also relevant to non-randomised controlled evaluations and **realist evaluations** (see Parts 2 and 3 of this book).

Community involvement can contribute to the design of evaluations by identifying the most appropriate geographic areas for the research and, in the case of trials, appropriate units for **randomisation** and locally appropriate randomisation methods. For example, as part of the preparation for a trial of an intervention to prevent violence against women in Samoa, community members shared that some villages have

community committees that enforce penalties for domestic violence, while others do not, and these penalties shape how communities respond to violence against women (Mannell and Prost, 2023). These discussions led to the trial team stratifying the trial's randomisation to ensure that communities with strict penalties for violence would be equally distributed between intervention and control groups. In addition, given competition between communities, the study team and communities also took the decision to conduct a public randomisation where community names would be randomly drawn from a bowl with local media present, to promote transparency.

Community involvement can also be used to inform or drive the collection and analysis of impact and **process evaluation** data. For example, communities can provide insights about which **variables** to collect data on and how. They can also directly inform protocols and data analysis plans by helping to select primary outcomes, identifying criteria for 'success' or taking part in participatory statistics exercises. In the context of the aforementioned JIAH trial for adolescent health, for example, community members and the NGO Ekjut contributed to defining primary outcomes after working on a theory of change for the intervention. Because the trial had three joint primary outcomes, they also co-developed criteria to define what might constitute sufficient success to support further intervention scale up. Finally, adolescent group members took part in a participatory exercise where they voted for the main health, education and wellbeing outcomes they thought had changed. This analysis was compared to that of the 'independent' data collection for the trial and found to both confirm and augment it (Bhatia et al., *under review*).

Public health researchers often work with community health advisory boards to support community involvement in efficacy evaluations of complex public health interventions. Box 3.4 offers an in-depth case study on the benefits and challenges of working with such boards, building on Zambian expertise in HIV research.

3.3.4 Evaluating interventions at scale, in routine settings

Finally, there are several benefits to community involvement in the evaluation of complex, routinely implemented public health interventions.

First, community involvement ensures that interventions implemented at scale, as well as their evaluation designs, are relevant and appropriate. Engaging communities in refining interventions, from their design for 'proof of concept' efficacy trials to a design suitable for broader implementation, offers an opportunity to further align interventions with local norms, values and practices. For instance, Rabin et al. (2023) designed a multi-level, longitudinal, mixed-methods study to evaluate the sustained impact of a multicomponent strategy promoting equitable COVID-19 vaccine uptake among underserved communities in Southern California. Both the intervention and study design were developed by researchers in partnership with community advisory boards led by 'community weavers' – individuals with lived experience in underserved

BOX 3.4 WORKING WITH COMMUNITY ADVISORY BOARDS

Lessons from Zambia

The PopART intervention aimed to reduce HIV **incidence** using a combination prevention package that included universal testing and treatment delivered door-to-door by study-specific community health workers, called Community HIV Care Providers (CHiPs). The CHiPs promoted knowledge of HIV status, offered home-based HIV testing and supported linkage to care and treatment for people living with HIV (PLWH). The HPTN 071 (PopART) study was a community RCT, which evaluated the effectiveness of two intervention packages on HIV incidence over a three-year period. The study was carried out in 21 communities in Zambia (12) and in the Western Cape, South Africa (9), with a combined population of over one million (Cori et al., 2014; Hayes et al., 2014; Hayes et al., 2019). This case study is based on the Zambian experience.

PopART was one of the biggest universal test and treat studies ever conducted, and its successful implementation rested in part with the extent to which participating communities were involved throughout. A consultation meeting was held for district, national and community-level representatives prior to writing the full proposal and securing funding. The community representatives were former Community Advisory Board (CAB) members from a large HIV/TB community randomised study, the ZAMSTAR study, that was previously conducted by Zambart, a research NGO. This meeting highlighted concerns from community members, one of which was the possibility that young people might engage in unprotected sex if they thought that early antiretroviral therapy (ART) would protect them from HIV infection. CAB members suggested clearer messaging and the involvement of young people. Following receipt of funding, a major decision was made to co-create new CABs and not to use the old ones in all the 12 Zambian communities, with a national CAB overseeing community-level CABs. This was because the old CABs in previous studies did not include some voices critical to the PopART study, such as individuals openly living with HIV. This was a challenge throughout the study's implementation. To remedy this, interaction with as many stakeholders as possible became the mainstay of community involvement activities in the PopART study. A Community Partners Platform (CPP) was also created to represent the voices of TB/HIV and treatment literacy-related civil society organisations. The CPP had dedicated funding from the study, and even monitored study activities through field visits (Simwinga et al., 2016).

CAB members were trained in research ethics, including good participatory practice, core facilitation skills, and how to read and interpret protocols. This helped them to adequately fulfill both the instrumental and intrinsic goals of community

involvement. For example, CAB members were involved in suggesting recruitment and retention strategies. A major challenge the study faced one year into implementation was the low uptake of the intervention by men. CAB members participated in the co-development of appropriate key messages and the involvement of men in approaches, which improved acceptability of the PopART intervention for men. The CABs also participated in the study exit activities and dissemination of findings in an elaborate and co-produced process using a community dialogue approach (Simwinga et al., 2022). With regards to intrinsic goals, CABs enhanced the ethical conduct of the study in several ways. They recommended the repositioning of counselling booths in one community to enhance privacy, and also indirectly protected study participants and the community in general by reporting on any incidents or social harms related to the study being talked about in the community. These were then further investigated to determine their relation to the PopART study and reported accordingly using the study oversight procedures. Adolescent CABs were later established when a study on young people was funded to collect research data on young people's participation in the PopART intervention (Shanaube et al., 2017). Researchers' respect for the CABs continued to grow. However there were situations when some sections of PopART researchers did not agree with the CABs' decisions and wondered whether the CAB had considered the impact of their decisions on study implementation and outcomes. One such occasion was the prospect of destroying a lot of Information, Education and Communication (IEC) material because a change, which the CAB had insisted on, was mistakenly left in the printed material. The community engagement team held meetings with the CAB and intervention team to resolve the matter, which ended in the understanding by the latter that the CABs were as interested in the scientific rigour of the study as everyone else, but that they were also concerned about the community's and study participants' welfare – an **accountability** role they played as community representatives.

communities – who also acted as cultural brokers between communities, public health systems, researchers and care providers.

Second, community-based participatory research can be used within the evaluation of complex public health interventions at scale to ensure interventions remain feasible, acceptable and retain their intended effects (Israel et al., 2010; Wallerstein et al., 2019). Ramanadhan et al. (2023) propose a framework for integrating participatory methods in evaluative research at scale, emphasising collaboration between health providers, patients and policymakers. This framework recognises that joint research often involves nonlinear and emergent processes. In their view, rather than merely adapting interventions to function within harmful systems, communities of practice

comprising diverse stakeholders should focus on reshaping systems to promote equity. In evaluation, this approach means capturing both traditional outcomes (for example, an intervention's **reach**) and transformative outcomes, such as knowledge sharing or building collective power and agency. For example, Restar et al. (2023) distilled lessons from gender-affirming programmes designed to increase access to HIV pre-exposure prophylaxis for transgender people at scale. The most impactful evaluations involved trans-led provider and community advisory boards and went beyond traditional metrics (for example, the number of clients served) to focus on systems-level outcomes, such as trans people's leadership in governance, and their individual and collective agency. These examples illustrate how community involvement can transform evaluations of interventions implemented in routine settings, often at scale, towards transformative outcomes for systems and people.

Having offered examples of how community involvement can enhance and even transform public health evaluation across the research cycle, we conclude this chapter with a summary and reflective exercise on community involvement in the context of evaluative research.

3.4 SUMMARY

In this chapter, we have learned about the importance of defining 'community'. We have highlighted that definitions of community can relate to shared place, identity, health condition, or focus on shared goals, and include a wide range of stakeholders, such as researchers, members of the public, patients, health providers and policymakers. We have described different levels of community involvement, from consultation to co-production. Finally, we have offered examples of how community involvement can enhance all stages of the evaluation research cycle, from identifying research questions to developing feasibility and acceptability study designs, and from evaluating efficacy in small-to-medium studies to implementation in routine settings, at scale.

3.5 SELF-DIRECTED LEARNING EXERCISE

A research group based in the public health unit of a major urban community has been tasked with developing and evaluating an intervention to support children's physical, mental and educational recovery following floods, which have become more frequent and severe due to climate change. Using the stages of the UK MRC framework for the development and evaluation of complex interventions, consider the following scenarios and questions. This exercise encourages you to reflect critically on the complexities of developing and evaluating interventions through meaningful community involvement.

Questions

Identifying the intervention

1. Community definition: What are the implications of defining a community based on characteristics (for example, children) versus as a group engaged in shared action? How might this influence who is included in community involvement efforts, and how?
2. Stakeholder inclusion: What are the potential benefits of involving children, parents, teachers and local government workers in defining or designing the intervention? What challenges might arise from such diverse participation?

Piloting

The research team, along with advisory groups consisting of children, teachers and parents, decides to involve children who have experienced floods in creating 'flood manifestos' (as in Mort et al., 2018). These manifestos aim to articulate and disseminate locally feasible actions that have previously supported children and families in recovering from floods.

- An initial pilot shows that developing the manifestos is both feasible and accessible. However, the research team and advisory groups differ on which health and wellbeing outcomes to evaluate.
  - Teachers want to focus on educational outcomes.
  - Parents prioritise mental health outcomes.

3. How would you approach this situation to reconcile differing priorities?
4. What trade-offs might be necessary to ensure the evaluation is meaningful to all stakeholders?

Evaluating effectiveness

- The local government agrees to support an evaluation of the flood manifestos. The researchers propose investigating the impact of the manifestos through a non-randomised study, using other flood-affected communities that did not develop manifestos as the comparison group.
- However, children and parents oppose using a comparison group, believing that the manifestos are more likely to bring benefit than harm.

5. What are the pros and cons of the researchers' proposed approach?
6. How might you address concerns from children and parents while maintaining scientific rigour in the evaluation?

Long-term implementation

The effectiveness evaluation reveals that:

- The manifestos increased preparedness among children and families.
- Children who developed the manifestos reported an enhanced sense of agency.
- However, the manifestos did not significantly improve children's mental health or educational outcomes following floods.

7. Who should make decisions about the long-term implementation of the flood manifesto intervention and its future evaluation?
8. What considerations should guide these decisions, and why?

For suggested solutions or answers to the exercise, please see the resources tab at https://uclpress.co.uk/book/evaluating-public-health-interventions

REFERENCES

Arnstein, S. R. (1969) 'A ladder of citizen participation'. *Journal of the American Institute of Planners*, 35(4), 216–24.

Barr, D., Garnett, G., Mayer, K. H. and Morrison, M. (2021) 'Key populations are the future of the African HIV/AIDS pandemic'. *Journal of the International AIDS Society*, 24 (Suppl 3), e25750.

Berenstain, N. (2016) 'Epistemic exploitation'. *Ergo*, 3(22), 569–88.

Bhatia, K., Rath, S., Pradhan, H., Samal S., Copas, A., Gagrai, S., Rath, S., Gope, R., Nair, N., Tripathy, P., Rose-Clarke, K. and Prost, A. (2022) 'Effects of community youth teams facilitating participatory adolescent groups, youth leadership activities and livelihood promotion to improve school attendance, dietary diversity and mental health among adolescent girls in rural eastern India (JIAH trial): A cluster-randomised controlled trial'. *SSM Population Health*, 21, 101330.

Bhatia, K., Samal, S., Rath, S., Pradhan, H., Copas, A., Gagrai, S., Rath, S., Gope, R., Nair, N., Tripathy, P., Rose-Clarke, K. and Prost, A. (under review) 'Comparing community-led participatory impact assessment with survey-based evaluation of a community-based intervention to improve adolescent health: Secondary analysis of a cluster-randomised controlled trial in rural eastern India'.

Bonney, R., Cooper, C. B., Dickinson, J., Kelling, S., Phillips T., Rosenberg, K. V., Shirk, J. L. (2009) 'Citizen science: A developing tool for expanding science knowledge and scientific literacy'. *BioScience*, 59(11), 977–84.

Burgess, R. A. (2023) *Rethinking Global Health: Frameworks of power*. London: Routledge

Burgess, R. A. and Choudary, N. (2021) 'Time is on our side: Operationalising "phase zero" in coproduction of mental health services for marginalised and underserved populations in London'. *International Journal of Public Administration*, 44(9), 753–66.

Burgess, R. A. (2022) 'Working in the wake: Transformative global health in an imperfect world'. *BMJ Global Health*, 7(9), e010520.

Campbell, C. and Jovchelovitch, S. (2000) 'Health, community and development: Towards a social psychology of participation'. *Journal of Community and Applied Social Psychology*. 10(4), 255–70.

Clasen, T., Boisson, S., Routray, P., Torondel, B., Bell, M., Cumming, O., Ensink, J., Jenkins, M.,Odagiri, M., Ray, S., Sinha, A., Suar, M. and Schmidt, W-P. (2014) 'Effectiveness of a rural sanitation programme on diarrhoea, soil-transmitted helminth infection, and child malnutrition in Odisha, India: A cluster-randomised trial'. *Lancet Global Health*, 2(11), e645–53.

Cori, A., Ayles, H., Beyers, N., Schaap, A., Floyd, S., Sabapathy, K., Eaton, J. W., Hauck, K., Smith, P., Griffith, S., Moore, A., Donnell, D., Vermund, S. H., Fidler, S., Hayes, R., Fraser, C. on behalf of HPTN 071 (PopART) Study Team (2014) 'HPTN 071 (PopART): A cluster-randomized trial of the population impact of an HIV combination prevention intervention including universal testing and treatment: mathematical model'. *PLoS ONE*, 9(1), e84511.

Cornish, F., Breton, N., Moreno-Tabarez, U., Delgado, J., Rua, M., de-Graft Aikins, A. and Hodgetts, D. (2023) 'Participatory action research'. *Nature Reviews Methods Primers*, 3(1), 34.

Craig, P., Dieppe, P., Macintyre S., Michie, S., Nazareth, I., Petticrew, M. (2008) 'Developing and evaluating complex interventions: The new Medical Research Council guidance'. *BMJ*, 337, a1655.

Creighton, J. L. (2005) *The Public Participation Handbook*. San Francisco, CA: Jossey-Bass Publishing.

Doyle, A. M., Dziva Chikwari, C., Majozi, N., Simwinga, M., Mayingire, G. R., Simbeye, K., Dringus, S., Bernays, S. (2022) 'Adolescent Health Series: Engagement with young people as partners in health research: Four case studies from Sub-Saharan Africa' *Tropical Medicine & International Health* 27, 2–12.

Elmes, J., Stuart, R., Grenfell, P., Walker, J., Hill, K., Hernandez, P., Henham, C., Rutsito, S., Sarker, M. D., Creighton, S., Browne, C., Boily, M-C., Vickerman, P. and Platt, L. (2022) 'Effect of police enforcement and extreme social inequalities on violence and mental health among women who sell sex: Findings from a cohort study in London, UK'. *Sexually Transmitted Infections Journal*, 98(5), 323–31.

Filipe, A., Renedo, A. and Marston, C. (2017) 'The co-production of what? Knowledge, values, and social relations in health care' *PLoS Biology*, 15(5), e2001403.

Harris, M. (2020) 'An urgent impetus for action: Safe inhalation interventions to reduce COVID-19 transmission and fatality risk among people who smoke crack cocaine in the United Kingdom'. *International Journal of Drug Policy*, 83, 102829. https://doi.org/10.1016/j.drugpo.2020.102829.

Harris, M., Scott, J., Hope, V., Busza, J., Sweeney, S., Preston, A., Southwell, M., Eastwood, N., Vuckovic, C., McGaff, C., Yoon, I., Wilkins, L., Ram, S., Lord, C., Bonnet, P., Furlong, P., Simpson, N., Slater, H. and Platt, L. (2024) 'Safe inhalation pipe provision (SIPP): Protocol for a mixed-method evaluation of an intervention to improve health outcomes and service engagement among people who use crack cocaine in England'. *Harm Reduction Journal*, 21(1), 19.

Hayes, R., Ayles, H., Beyers, N., Sabapathy, K., Floyd, S., Shanaube, K., Bock, P., Griffith, S., Moore, A., Watson-Jones, D., Fraser, C., Vermund, S. H., Fidler, S., HPTN 071 (PopART) Study Team. (2014) 'HPTN 071 (PopART): Rationale and design of a cluster randomised trial of the population impact of an HIV combination prevention intervention including universal testing and treatment – a study protocol for a cluster randomised trial'. (2014) *Trials*, 15, 57.

Hayes, R. J., Donnell, D., Floyd, S., Mandla, N., Bwalya, J., Sabapathy, K., Yang, B., Phiri, M., Schaap, A., Eshleman, S. H., Piwowar-Manning, E., Kosloff, B., James, A.,

Skalland, T., Wilson, E., Emel, L., Macleod, D., Dunbar, R., Simwinga, M., Makola, N., Bond, V., Hoddinott, G., Moore, A., Griffith, S., Deshmane Sista, N., Vermund, S. H., El-Sadr, W., Burns, D. N., Hargreaves, J. R., Hauck, K., Fraser, C., Shanaube, K., Bock, P., Beyers, N., Ayles, H., Fidler, S. on behalf of HPTN 071 (PopART) Study Team (2019) 'Effect of universal testing and treatment on HIV incidence – HPTN 071 (PopART)'. *New England Journal of Medicine*, 381(3), 207–18.

Horowitz, C., Robinson, M. and Seifer, S. (2009) 'Community-based participatory research from the margins to the mainstream: Are researchers prepared?'. *Circulation*, 119(19), 2633–42.

Howard, N. (2022) 'Towards ethical good practice in cash transfer trials and their evaluation'. *Open Research Europe*, 2, 12.

Israel, B. A., Eng, E., Schulz, A. and Parker, E. A. (2013) 'Introduction to methods in community based participatory research'. In B. A. Israel, E. Eng, A. Schulz and E. A. Parker (eds), *Methods in Community-Based Participatory Research for Health*. Hoboken NJ: John Wiley & Sons, 3–26.

Israel, B. A., Coombe, C. M., Cheezum, R. R., Schulz, A. J., McGranaghan, R. J., Lichtenstein, R., Reyes, A. G., Clement, J. and Burris, A. (2010) 'Community-based participatory research: A capacity-building approach for policy advocacy aimed at eliminating health disparities'. *American Journal of Public Health*, 100(11), 2094–2102.

Kickbusch, I. and Gleicher, D. (2012) *Governance for Health in the 21st Century*. Copenhagen: World Health Organization (WHO) Regional Office for Europe.

Leal, P. A. (2007) 'Participation: The ascendancy of a buzzword in the neo-liberal era'. *Development in Practice*, 17, 539–48.

Lewin, K. (1946) 'Action research and minority problems'. *Journal of Social Issues*, 2(4), 34–46.

London, A. J. (2001) 'Equipoise and international human subjects research'. *Bioethics*, 15(4), 312–32.

MacQueen, K. M., McLellan, E., Metzger, D. S., Kegeles, S., Strauss, R. P., Scotti, L., Blanchard, L. and Trotter, R. T. (2001) 'What is community? An evidence-based

definition for participatory public health'. *American Journal of Public Health*, 91(12), 1929–38.

Madden, M. and Speed, E. (2017). 'Beware zombies and unicorns: Toward critical patient and public involvement in health research in a neoliberal context'. *Frontiers in Sociology*, 2, 7. https://doi.org/10.3389/fsoc.2017.00007

Mannell, J. and Prost, A. (2023) 'Using participatory methods in randomised controlled trials of complex interventions'. In C. P. Poth (ed), *The SAGE Handbook of Mixed Methods Research Design*. London: Sage Publishing, 245–55.

Masterson, D., Areskoug Josefsson, K., Robert, G., Nylander, E., Kjellström, S. (2022) 'Mapping definitions of co-production and co-design in health and social care: A systematic scoping review providing lessons for the future', *Health Expectations*, 25, 902–13.

McMellon, C., McCusker, P., Roesch-Marsh, A., Hall, L., Bartlett, T. and McDermott, R. (2023) 'Reconceptualising coproduction as activism together'. *Children & Society*, 38(3), 804–22.

Mellor, K., Albury, C., Dutton, S. J., Eldridge S. and Hopewell, S. (2023) 'Recommendations for progression criteria during external randomised pilot trial design, conduct, analysis and reporting'. *Pilot and Feasibility Studies*, 9, 59.

Mort, M., Walker, M., Williams, A. L. and Bingley, A. (2018). 'From victims to actors: The role of children and young people in flood recovery and resilience'. *Environment and Planning C: Politics and Space*, 36(3), 423–42.

National Institute of Health and Care Research (NIHR) (2021) 'Briefing notes for researchers – public involvement in NHS, health and social care research'.Accessed 5 October 2024. https://www.nihr.ac.uk/briefing-notes-researchers-public-involvement-nhs-health-and-social-care-research.

O'Cathain, A., Croot, L., Duncan, E., Rousseau, N., Sworn, K., Turner, K. M., Yardley, L. and Hoddinott, P. (2019) 'Guidance on how to develop complex interventions to improve health and healthcare'. *BMJ Open*, 9(8), e029954.

Office of the United Nations High Commissioner for Human Rights (OHCHR) (2014) 'Module 4: Measures for implementation'. *OHCHR Training Package on the*

Convention on the Rights of Persons with Disabilities. Geneva: OHCHR. Accessed 30 December 2024. https://www.ohchr.org/en/disabilities/ohchr-training-package-convention-rights-persons-disabilities.

Olakunde, B. O. and Adeyinka, D. A. (2024) 'Uncertainty in key population size estimates in sub-Saharan Africa'. *The Lancet Global Health*, 12(9), e1371.

Osrin, D., Azad, K., Fernandez, A., Manandhar, D. S., Mwansambo, C., Tripathy, P., Costello, A. (2009) 'Ethical challenges in cluster randomized controlled trials: Experiences from public health interventions in Africa and Asia'. *Bulletin of the World Health Organization*, 87(10), 772–9.

Partnership for Maternal, Newborn and Child Health, Family Planning 2020 and International Youth Alliance for Family Planning (2020) 'Global consensus statement on meaningful adolescent and youth engagement'. Accessed 5 October 2024. https://pmnch.who.int/resources/publications/m/item/global-consensus-statement-on-meaningful-adolescent-and-youth-engagement..

Rabin, B. A., Cain, K. L., Watson, P. Jr., Oswald, W., Laurent, L. C., Meadows, A. R., Seifert, M., Munoz, F. A., Salgin, L., Aldous, J., Diaz, E. A., Villodas, M., Vikaykumar, S., O'Leary, S. T. and Stadnick, N. A. (2023) 'Scaling and sustaining COVID-19 vaccination through meaningful community engagement and care coordination for underserved communities: Hybrid type 3 effectiveness-implementation sequential multiple assignment randomized trial'. *Implement Science*, 18(1), 28.

Ramanadhan, S., Aleman, R., Bradley, C. D., Cruz, J. L., Safaeinili, N., Simonds, V. and Aveling, E-L. (2023) 'Using participatory implementation science to advance health equity'. *Annual Review of Public Health*, 45(1), 47–67.

Restar, A., Minalga, B. J., Quilantang, M. I., Adamson, T., Dusic, E., van der Merwe, L-A., Millet, G., Rosadiño, D., Laguing, T., Lett, E., Everhart, A., Phillips, G., Janamnuaysook, R., Seekaew, P., Baker, K., Ashley, F., Wickersham, J., Wallace, S. E., Operario, D. and Gamarel, K. E. (2023) 'Mapping community engaged implementation strategies with transgender scientists, stakeholders, and trans-led community organizations'. *Current HIV/AIDS Reports*, 20(3), 160–69.

Ricciardo, B. M., Kessaris, H. L., Nannup, N., Tilbrook, D., Tilbrook, D., Farrant, B., Michie, C., Hansen, L., Douglas, R., Walton, J., Poore, A., Whelan, A., Barnett, T. C., Kumarasinghe, P. S., Carapetis, J. R. and Bowen, A. C. (2024) 'Describing skin

health and disease in urban-living Aboriginal children: Co-design, development and feasibility testing of the Koolungar Moorditj Healthy Skin pilot project'. *Pilot and Feasibility Studies*, 10, 6.

Rifkin, S. B. (2018) 'Alma Ata after 40 years: Primary health care and health for all – from consensus to complexity'. *BMJ Global Health*, 3 (Suppl 3), e001188.

Rigg, K. K., McNeish, R., Schadrac, D., Gonzalez, A. and Tran, Q. (2019) 'Community needs of minority male youth living in inner-city Chicago'. *Children and Youth Services Review*, 98, 284–9.

Shanaube, K., Schaap, A. B., Floyd, S., Macworth-Young, C., Hoddinott, G., Hayes, R., Fidler, S., Ayles, H. on behalf of the HPTN 071 (PopART) Study Team. (2017) 'Community intervention improves knowledge of HIV status of adolescents in Zambia: Findings from HPTN 071-PopART for youth study'. *AIDS*, 31 (Suppl 3), S221–32.

Simwinga, M., Bond, V., Makola, N., Hoddinott, G., Belemu, S., White, R., Shanaube, K., Seeley, J., Moore, A. on behalf of HPTN 071 (PopART) Study Team. (2016) 'Implementing community engagement for combination prevention: Lessons learnt from the first year of the HPTN 071 (PopART) community-randomized study'. *Current HIV/AIDS Reports*, 13(4), 194–201.

Simwinga, M., Ndubani, R., Schaap, A., Ziba, D., Bwalya, C., Belemu, S., Ngwenya, F., Bwalya, J., Shanaube, K., Hoddinott, G., White, R., Bock, P., Fidler, S., Hayes, R., Seeley, J., Ayles, H., Bond, V. on behalf of the HPTN 071 (PopART) Study Team (2022) 'Disseminating complex primary outcome results from a community-randomised trial to Zambian communities: Lessons learned using a community dialogue approach in the HPTN 071 (PopART) trial'. *The Lancet HIV*, 9(11), e801–8.

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M. and Moore L. (2021) 'A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance'. *BMJ*, 374, n2061.

Smith, L. T. (1999) *Decolonizing Methodologies: Research and Indigenous Peoples* (2nd ed.). London and New York: Zed Books.

Strumińska-Kutra, M. and Scholl, C. (2022) 'Taking power seriously: Towards a power-sensitive approach for transdisciplinary action research'. *Futures*, 135, 102881.

Walker, J. G., Elmes, J., Grenfell, P., Eastham, J., Hill, K., Stuart, R., Boily, M-C., Platt, L. and Vickerman, P. (2024) 'The impact of policing and homelessness on violence experienced by women who sell sex in London: A modelling study'. *Scientific Reports*, 14(1), 8191.

Wallerstein, N., Muhammad, M., Sanchez-Youngman, S., Rodriguez Espinosa, P., Avila, M., Baker, E. A., Barnett, S., Belone, L., Golub, M., Lucero, J., Mahdi, I., Noyes, E., Nguyen, T., Roubideaux, Y., Sigo, R. and Duran, B. (2019) 'Power dynamics in community-based participatory research: A multiple-case study analysis of partnering contexts, histories, and practices'. *Health Education and Behaviour: The Official Publication of the Society of Public Health Education*, 46 (Suppl 1), 19S–32S.

Wenger, E. (1996) 'How we learn. Communities of practice. The social fabric of a learning organization'. *Healthcare Forum Journal*, 39(4), 20–6.

White, S. C. (1996) 'Depoliticising development: The uses and abuses of participation'. *Development in Practice*, 6(1), 6–15.

World Health Organization (WHO) (2023) *WHO Framework for Meaningful Engagement of People Living with Noncommunicable Diseases, and Mental Health And Neurological Conditions*. Geneva: WHO.